AIDS IN AMERICA

November 6, 2008

Mr. John Podesta
Ms. Valerie Jarrett
Mr. Peter Rouse
Co-Chairs, Obama-Biden Transition Project
Washington, DC

Dear Mr. Podesta, Ms. Jarrett, and Mr. Rouse:

As leaders of national organizations who have come together under the "AIDS In America" umbrella representing persons infected and affected by HIV/AIDS, minority communities, gay men, women, HIV medical providers, HIV housing providers, AIDS service organizations, state AIDS programs, AIDS legal advocates, and AIDS nutrition providers, we congratulate Sen. Obama on his election. We look forward to working with President-elect Obama, his transition team, and his Administration on domestic HIV/AIDS issues. To that end, we offer the following recommendations for action by your Administration in the first 100 days of office.

This document is first and foremost a call for renewed leadership. It is a call for a comprehensive and adequately funded response to the domestic AIDS epidemic in the United States—which President-elect Obama called for himself during the campaign. Leadership on domestic HIV/AIDS issues must begin in the first 100 days of the Obama Administration and continue throughout your term of office.

We offer to you our expertise and passion as we work together on the difficult challenges facing our Nation, particularly in the area of HIV/AIDS. We hope you will call on us soon for assistance and hope we will have the opportunity to meet with your office soon. In order to arrange such a meeting, please contact Carl Schmid, Director of Federal Affairs, The AIDS Institute at 202-462-3042, CSchmid@theaidsinstitute.org or Andrea Weddle, Executive Director, HIV Medicine Association at 703-299-1215 , AWeddle@idsociety.org. We would be pleased to provide additional background information on these important issues at such a meeting or upon your request.

The organizations listed on the following page endorse the attached "AIDS In America" recommendations for the first 100 days of office of the 44th President of the United States.

Endorsements are listed alphabetically.

Rebecca Haag
Executive Director
AIDS Action Council

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William Smith
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William E. Arnold
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AIDS IN AMERICA
RECOMMENDATIONS FOR THE FIRST 100 DAYS OF OFFICE OF THE 44TH PRESIDENT OF THE UNITED STATES

Overview

More than 25 years into the AIDS epidemic, HIV infection continues to exact an enormous toll in the United States. According to the Centers for Disease Control and Prevention, more than a million people—an estimated 1,106,400 adults and adolescents—are living with HIV infection in the United States at the end of 2006. With 56,000 new infections occurring every year, over half of the people who know they are HIV positive not receiving adequate healthcare and treatment, and an estimated 21 percent of people who are HIV positive not being aware that they are infected, there is an AIDS crisis in the United States.

Gay and bisexual men of all races, African Americans, Hispanic/Latinos are the most heavily affected. While those who identify as Black make up only 12 percent of the U.S. population, they represented nearly half—or 46 percent—of all people living with HIV in the U.S. in 2006. African-American men bear the greatest burden of HIV; the prevalence rate for black men is six times as high as the rate for white men. African American women are also severely affected with a prevalence rate that is 18 times the rate of white women. The Hispanic/Latino community is also disproportionately affected by HIV. Those who identify as Hispanic/Latino comprise 15 percent of the U.S. population but they accounted for 18 percent of persons living with HIV in 2006. The prevalence rate for Latino men is more than twice the rate for white men and the prevalence rate for Latino women is four times the rate for white women.

In 2006, 48 percent of all people living with HIV in the U.S. were men who have sex with men; 53 percent of new HIV infections were estimated to occur among this population. Stigma and discrimination serve to marginalize gay and bisexual men in all communities; help to facilitate risk-taking behaviors, and silence accurate information about sexual risks. Also in terms of gender, women across all races and ethnicities represent a greater proportion of new HIV/AIDS cases, more than tripling from 8 percent of new cases in 1985 to 27 percent of new cases in 2006.

In August 2008, the CDC released a new estimate of annual HIV infections, indicating that the epidemic in the U.S. is worse than previously known with 56,300 new HIV infections occurring each year. Too many persons are still becoming infected with HIV in the U.S. Racism, poverty and homophobia have clearly played a major role as social determinants of HIV risk and vulnerability in the U.S. HIV/AIDS is found wherever there is limited access to vital services, such as quality education and health care, and high rates of homelessness, malnutrition, substance use, mental illness, incarceration and poverty. These conditions are endemic in many minority communities in the U.S. People of color are often vulnerable due to the structural disparities inherent in their every day lives, leaving them susceptible to HIV/AIDS and its comorbidities like diabetes, tuberculosis, heart disease, hypertension, and hepatitis A, B, and C. The federal government must collect and make accessible better and more timely data on HIV infection in communities of color.

Public health strategies are only as good as the evidence on which they are based. The federal government must help build sustainable capacity in communities to address HIV/AIDS not as a singular epidemic, but as part of an overall health crisis driven by social and structural disparities.

As national organizations representing persons infected and affected by HIV/AIDS, minority communities, gay men, women, HIV medical providers, HIV housing providers, AIDS service organizations, state AIDS programs, and AIDS legal advocates, we offer the following recommendations for action by the next Administration in the first 100 days of office.

This document is first and foremost a call for renewed leadership. It is a call for a comprehensive and adequately funded response to the domestic AIDS epidemic in the United States. That leadership must begin in the first 100 days of the next Presidential Administration.

NATIONAL AIDS STRATEGY:

THE U.S. MUST HAVE WHAT IT ASKS OF OTHER NATIONS IT SUPPORTS IN COMBATING AIDS – A NATIONAL STRATEGY. TO THAT END, WE

Call for the development of a National AIDS Strategy for the U.S. that is designed to lower HIV incidence, increase access to HIV care, and reduce racial disparities in the epidemic and integrate HIV with STD, viral hepatitis and TB programs at the local level. The Strategy should rely on evidence-based policy and programming, set ambitious and credible targets for improved outcomes, require annual reporting on progress towards goals, address social factors that increase vulnerability to infection, and engage multiple sectors (with equitable inclusion of persons living with HIV/AIDS) in development of the Strategy.

As part of the National AIDS Strategy, we call for a coordinated federal response to preventing and treating HIV/AIDS to set the stage for the development of cross-Departmental programmatic standards and outcome data that are based on scientific evidence, high quality and high accountability. Coordination should occur between (and within) the Health Resources and Services Administration (HRSA), Centers for Medicare and Medicaid Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH) including the Office of AIDS Research (OAR), National Institute on Alcohol Abuse and Alcoholism (NIAAA), National Institute on Drug Abuse (NIDA), National Institute on Mental Health (NIMH), Department of Housing and Urban Development (HUD), Department of Veterans Affairs (VA), Department of Education, Department of Defense, Department of Justice – Federal Bureau of Prisons and related state agencies. [For additional information on the National AIDS Strategy go to: www.nationalaidsstrategy.org.]

FEDERAL FUNDING FOR HIV/AIDS PROGRAMS:

THE FEDERAL FUNDING COMMITMENT TO DOMESTIC HIV/AIDS HAS BEEN WOEFULLY INADEQUATE FOR TOO MANY YEARS. AS A RESULT MANY COMMUNITIES ARE STRUGGLING TO MEET THE PREVENTION AND CARE AND TREATMENT NEEDS OF PEOPLE AT RISK FOR OR LIVING WITH HIV AND OUR PROGRESS IN DEVELOPING NOVEL THERAPIES AND PREVENTION TECHNOLOGIES IS IN JEOPARDY. WE ASK THAT YOU -

In finalizing the FY2009 Appropriations bills, support the higher number between the House and Senate bills in order to provide support to HIV prevention, care, treatment, research, and housing programs. In those instances where both the House and Senate have proposed flat funding, we request that you support an increase of not less than 5 percent. Additionally, we are proposing increases higher than either the House or Senate proposals for CDC and NIH HIV programs. The request levels are detailed below.

In preparing the President's budget proposal for FY2010, make public health and HIV/AIDS a priority. Below are the community's funding request levels for FY2009 that can be used as a guide for laying down a funding marker for Congress to follow as you prepare your fiscal year 2010 budget. These do not represent the true need, which are higher in each instance.

U.S. Department Of Health And Human Services

Centers for Disease Control and Prevention

The number of people living with HIV in the U.S. is rising while HIV prevention funding has been cut the past six years. We support the professional judgement budget recently offered by the CDC that concludes "with an additional $877 million in FY 2009 (an additional $4,784 million over 5 years), CDC could greatly expand its efforts, increasing coverage and impact, and could provide leadership to an effective U.S. response to the epidemic at home." Even beyond the human impact -- this investment would result in greater overall savings to the health care system. Before the annual HIV incidence number was increased to 56,000 -- it was estimated that preventing 40,000 new HIV infections in the U.S. each year would save $12.1 billion in annual medical costs. Clearly investing in prevention is cost-effective.

• Increase funding for HIV Prevention and Surveillance by at least $200 million in FY2009 and $877 million in FY2010 for a total of at least $1.569 billion.

• Increase funding for the Division of Adolescent and School Health (DASH), which in part supports the development and implementation of effective health promotion policies and programs that address HIV prevention among youth, by $2 million in FY2009 and by $26.4 million in FY2010 for a total of at least $66.6 million.

Ryan White HIV/AIDS Programs

The Ryan White Program provides life extending healthcare, drug treatment and support services to 531,000 low-income, uninsured and underinsured individuals and families affected by HIV/AIDS each year.

• Increase overall funding for the Ryan White Program by $100 million in FY2009 and $614.49 million in FY2010 for a total of at least $2.78 billion.

• Increase funding for Part A, which provides care and support to 56 metropolitan areas, by $42.9 million in FY2009 and by $213 million in FY2010 for a total of at least $840 million.

• Increase funding for the Part B Base, which provides healthcare to people in all states and territories by $14.5 million in FY2009 and by $95 million in FY2010 for a total of at least $482 million.

• Increase funding for the AIDS Drug Assistance Program (ADAP), which provides lifesaving drug treatment, by $28.3 million in FY2009 and by $134.6 million in FY2010 for a total of at least $943.5 million.

• Increase funding for Part C, which supports healthcare at 363 directly funded clinics, by $6.2 million in FY2009 and by $100.5 million in FY2010 for a total of at least $299 million.

• Increase funding for Part D, which provides services to women, children, youth and families, by $6.3 million in FY2009 and by $48.8 million in FY2010 for a total of at least $122.5 million.

• Increase funding for the AIDS Education and Training Centers, which train health care providers who care for people with HIV/AIDS, by $0.6 million in FY2009 and by $15.9 million in FY2010 for a total of at least $50 million.

• Increase funding for the Dental Reimbursement Program, which provides access to dental care for people living with HIV/AIDS, by $1.1 million in FY2009 and by $6 million in FY2010 for a total of at least $19 million.

Minority AIDS Initiative (MAI)

Increase funding for the Minority AIDS Initiative, which supports programs across eight agencies targeted at improving HIV-related health outcomes and reducing disparities for racial and ethnic minority groups, by $20.1 million in FY2009 and by $223 million in FY2010 for a total of at least $610 million.

National Institutes of Health (NIH)

AIDS research supported by NIH is critical for new drug development, diagnostics and disease prevention, including behavioral research and research on vaccines and microbicides.

• Increase overall funding for the NIH by $1.65 billion in FY2009 and by $4.38 billion in FY2010 for a total of at least $33.58 billion and include an increase of $450 million for HIV/AIDS Research for a total of at least $3.35 billion.

U.S. Department of Housing And Urban Development (HUD)

• Increase funding for the Housing Opportunities for Persons with AIDS program, which provides housing assistance to low-income people living with AIDS and their families, by $15 million in FY2009 and by $169 million in FY2010 for a total of at least $470 million.

Make the most effective use of federal dollars and promote sound public health policies by taking the following actions:

• Support lifting the federal ban contained in appropriation bills on all syringe exchange programs to allow for the broader implementation and scale up of evidence-based, proven effective, HIV prevention programs for injecting drug users. This could be achieved through a statement in your FY2010 budget as well as public support for Congressman Jose Serrano's (D-NY) "Community HIV/AIDS and Hepatitis Prevention Act" (HR 6680 in the 110th Congress) which would effectively end the ban on use of federal funds for syringe exchange programs.

• Support evidenced-based sexuality education by discontinuing funding for abstinence-only until marriage programs, including those funded through: the Community-Based Abstinence Education (CBAE) and redirecting such funding to the CDC DASH to support comprehensive evidence-based prevention programs.

PREVENTION:

IT IS TIME TO SCALE UP HIV PREVENTION IN THE U.S. BY SUPPORTING A COMPREHENSIVE HIV PREVENTION STRATEGY THAT IS BASED ON EVIDENCE NOT IDEOLOGY. TO THAT END, WE URGE YOU TO –

Direct the CDC to develop prevention programs that focus on the communities and populations that are most at risk for HIV disease.

Direct the Secretary of Health and Human Services to certify that syringe exchange is an effective intervention for reducing the spread of infectious diseases, such as HIV and hepatitis C, and it does not increase drug use.

Support evidenced-based sexuality education by discontinuing funding for abstinence-only until marriage programs, including those funded through: Title V, the Community-Based Abstinence Education (CBAE) program and related programming operating under the same guidance in the Adolescent Family Life Act (AFLA) and redirecting such funding to the CDC DASH to support comprehensive evidence-based prevention programs.

Until they are eliminated, direct the Department of Health and Human Services to require that all programs receiving abstinence-only-until-marriage funding provide written assurances that they will not misrepresent or provide inaccurate information regarding the effectiveness and reliability of condoms.

Direct the Department of Justice to issue guidelines to ensure that inmates in federal prisons are offered voluntary, non-coercive, confidential, informed HIV testing and that all inmates are provided continued HIV prevention education. Agency guidelines should allow for the provision of HIV counseling and testing services by community-based service providers.

Direct the Department of Justice to require federal prisons to develop, adopt and implement comprehensive HIV prevention programs to educate HIV negative inmates about avoiding HIV infection and educating HIV-positive inmates about how to avoid transmitting HIV to others. Distribute sexual barrier devices and provide access to comprehensive healthcare and treatment to inmates with HIV/AIDS.

Continue funding for existing programs to prevent mother to child transmission as well as for the Expanded Testing Initiative through grants to community-based programs and cooperative agreements with state and local health departments in lieu of funding for the Early Diagnosis Grant program.

Eliminate barriers to public and private reimbursement for HIV testing in health care settings. Testing only individuals with symptoms or identified as being part of a high-risk category often excludes women and other groups who are at risk for HIV infection.

ACCESS TO CARE:

IN 2004, THE INSTITUTE OF MEDICINE ESTIMATED THAT MORE THAN 50 PERCENT OF PEOPLE LIVING WITH HIV IN THE U.S. DID NOT HAVE RELIABLE ACCESS TO THE CARE THAT THEY NEEDED TO STAY ALIVE. WITH MORE THAN TWO-THIRDS OF PEOPLE WITH HIV/AIDS RELYING ON FEDERAL PROGRAMS FOR ACCESS TO CARE, WE MUST DO BETTER AT ENSURING THAT THESE PROGRAMS AND THEIR POLICIES SUPPORT EARLY AND RELIABLE ACCESS TO THE RANGE OF SERVICES AND MEDICAL PROVIDERS THAT PEOPLE WITH HIV NEED TO STAY HEALTHY. WE URGE YOU TO TAKE THE FOLLOWING STEPS TO IMPROVE ACCESS TO CARE THROUGH THE FEDERAL PROGRAMS THAT ARE CRITICAL TO PEOPLE WITH HIV/AIDS.

Health Care Reform

Launch a universal health care reform initiative in the first 100 days of office.

Ensure that HIV medical providers, social service providers, advocates, public health programs and people living with HIV play a key role in the development of a plan to reform the U.S. health care financing and delivery system.

Call for the services currently provided by the Ryan White programs that may not be encompassed in a health care reform plan, such as housing, to continue and for seamless integration of Ryan White-funded services with the broader health care system.

Ryan White Program

Call for Congress to pass a simple three-year extension of the Ryan White HIV/AIDS Treatment Modernization Act to allow adequate time to implement and evaluate the significant policy and program changes included in the 2006 reauthorization. This critical program will sunset on September 30, 2009 if no action is taken.

Call for the HRSA HIV/AIDS Bureau (HAB) to:

• Restore local and state decision making on the funding of transitional housing services for people with HIV/AIDS by retracting the cumulative 24 month lifetime cap on Ryan White Parts A and B coverage of transitional housing established by HRSA's HIV/AIDS Bureau.

• Conduct a rapid assessment of the state of HIV care and treatment in jurisdictions known to be experiencing administrative difficulties that are contributing to poor outcomes for people with HIV/AIDS -- e.g., Puerto Rico and New Orleans -- within 90 days of taking office and develop a comprehensive corrective action plan that could include immediate direct federal intervention if necessary to ensure access to the U.S. standard of HIV care and treatment to low income people with HIV/AIDS through Ryan White-funded services and other federally-supported programs, such as Medicaid.

• Revise the AIDS Drug Assistance Program (ADAP) guidance regarding pharmaceutical rebates such that the rebates are not treated as program income and discontinue the requirement that the rebates must be spent prior to their federal grant award.

• Direct HRSA to explore medically prescribed food and nutrition services as a core medical service and to evaluate whether clients for whom a nutritional plan is developed through medical nutrition therapy have access to the food outlined in the plan.

• Develop a waiver process that provides flexibility to grantees with unobligated funds of more than 2 percent of their grant award remaining at the end of the fiscal year to carry-over the funds due to factors such as large funding increases and shortened time frames for spending grant dollars.

• Release the HIV/AIDS data used to make Ryan White formula allocations and the Part A supplemental scores so that jurisdictions can better predict and prepare for funding shifts.

• Issue guidance affirming the ability of Ryan White Part D grantees to provide the continuum of services necessary to support optimal health and to retain children, youth and families in care through collaboration with other payers to ensure that Ryan White remains the payer of last resort for all services, including outpatient ambulatory care and primary medical care.

Medicaid

Provide access to lifesaving health care for all low income persons with HIV in the U.S., including those not yet disabled by AIDS, by calling for legislation that would establish a federal program to provide comprehensive health care services to persons with HIV infection below 250 percent of the federal poverty level. This program should be based on the recommendations of the Institute of Medicine (IOM) report "Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White." The IOM concluded that a national entitlement program was the most effective strategy for providing reliable and comprehensive care to low income people with HIV regardless of where they live. As recommended by the IOM, the Ryan White Program would continue to play a critical role by filling gaps in coverage for individuals not eligible for the new program and supporting the range of support and social services that have proven essential to successful HIV treatment, such as stable housing.

As interim measures, call for immediate passage of the "Early Treatment for HIV Act" or bypass the legislative process and waive budget neutrality on public health grounds to make it feasible for states to apply for Medicaid waivers aimed at expanding Medicaid eligibility to low income individuals with HIV infection not yet disabled by AIDS.

Ensure that Medicaid payments for HIV services are adequately reimbursed for the provision of quality care by qualified HIV medical experts.

Direct the Director of the CMS to Issue a Dear State Medicaid Director letter encouraging Medicaid coverage for HIV screening, and describing mechanisms for reimbursement.

Direct the CMS Director to create an advisory council of Medicaid providers and beneficiaries and beneficiary advocates, including Medicaid beneficiaries with HIV/AIDS, HIV medical providers and HIV advocates, under the CMS Medicaid Director.

Medicare

Direct the CMS Director to do the following:

Interpret the Medicare Part D statute to allow ADAP payments to count towards the true out of pocket cost limit or "TrOOP."

Allow ADAPs to access the data for low-income subsidy beneficiaries so they can better coordinate their drug coverage.

Strengthen protections for access to lifesaving medicines under Medicare Part D by promulgating regulations that require prescription drug plans to cover all HIV antiretroviral medications in all Part D formularies and to cover new antiretrovirals within 90 days of FDA approval.

Conduct a study to evaluate the impact of Medicare Part D on people with HIV that are dually eligible for Medicaid and Medicare and a broader study on the impact of Part D, especially the break in coverage known as the "donut hole", on people with HIV with Medicare-only coverage.

Allow peer reviewed literature to be considered for exceptions requests for coverage for off label indications under Medicare Part D (as is currently the case for cancer drugs under Medicare Part B).

Publicly release Medicare Part D data for antiretrovirals, including negotiated drug prices and the outcomes for exceptions and appeals cases.

HIV Clinical Workforce

Direct HHS to evaluate the capacity of the HIV clinical workforce regionally and nationally and develop recommendations and initiatives to respond to shortages in qualified medical personnel.

Substance Use Treatment and Mental Health Services

Announce a commitment to ensure that all Americans have access to comprehensive mental health and substance use treatment services through expansion of federal programs and parity requirements for private and public payers and through the enactment of universal health care reform.

Corrections

Direct the Department of Justice to issue policies and implementing guidelines to ensure that HIV-infected inmates are provided prompt, confidential health care in keeping with medical standards of care consistent with all of the HIV prevention, care and treatment guidelines developed by agencies within the US Department of Health and Human Services. Ensure that individuals released from custody receive appropriate discharge planning including linkages to uninterrupted healthcare.

RESEARCH:

OUR PROGRESS IN HIV TREATMENT AND PREVENTION WILL NOT BE SUSTAINED IF WE CONTINUE ON OUR CURRENT COURSE. OUR POLICIES MUST SUPPORT THE SCIENTIFIC PROCESS BY FACILITATING THE COORDINATION, DISCUSSION AND DISSEMINATION OF IDEAS AND RESEARCH FINDINGS AND FOSTERING THE NEXT GENERATION OF SCIENTISTS.
TO DO SO, WE URGE YOU TO –

Support the original intent, mission, and authorities of the Office for AIDS Research (OAR) to identify strategic opportunities to advance HIV research while ensuring the most effective and efficient coordination of AIDS research at the National Institutes of Health (NIH). Place a priority on supporting newly emerging researchers and those whose work is focused on the populations most heavily burdened by the HIV epidemic. Eliminate restrictions on the number of federal scientists allowed to participate in domestic and international HIV/AIDS conferences to assure the highest level of scientific exchange at such forums is achieved by the participation of U.S. scientists.

This document was completed in fond memory of Dr. Gene Copello who as the Executive Director of The AIDS Institute spearheaded this collaboration and this important effort.

CIVIL RIGHTS:

WE MUST UPDATE OUR FEDERAL POLICIES TO REFLECT THE LATEST AVAILABLE SCIENCE AND OFFER INCENTIVES TO STATES TO DO THE SAME. TOO MANY POLICIES STILL EXIST THAT DISCRIMINATE AGAINST PEOPLE WITH HIV/AIDS. WE URGE YOU TO END THESE HARMFUL PRACTICES AND POLICIES AND –

Issue an Executive Order to ensure that all federal agencies are complying with the Rehabilitation Act, to bar them specifically from using HIV infection as a basis for excluding or placing other medically-unwarranted restrictions on applicants, candidates or employees from any position; and to require that all federal agencies individually assess whether an individual with HIV can perform the functions of the position or activity and whether a reasonable accommodation can be made for that person, if necessary, to permit the individual's employment or inclusion.

Direct the CDC to update recommendations regarding health care workers with HIV and Hepatitis B—"Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures" -- to clarify the negligible risk to patients such health care workers present.

Direct the Department of Justice to respond to states' exclusion of people with HIV from occupational training schools and licensing by issuing official guidance or a directive letter to state officials/agency heads noting that the exclusion of persons with HIV/AIDS from such training programs and professional licensing is in violation of the Americans with Disabilities Act (ADA).

Direct the Department for Homeland Security to ensure the adequacy of care for immigrant detainees by increasing inspections by the Inspector General; revising the Medical Care Detention Standards, including provisions related to HIV, to conform to nationally recognized standards requiring medical care equivalent to that afforded in the community. Add non-discrimination provisions to the Detention Standards and promote alternatives to detention for immigrants with HIV.

Direct the Federal Bureau of Prisons to incorporate the confidentiality provisions included in the CDC's HIV testing guidance into their regulations and prioritize funding for corrections-based HIV care and prevention initiatives to jurisdictions and programs that adopt similar policies for protecting inmate confidentiality.

Call for the Secretary of HHS to rapidly develop regulations implementing the recent change in law that allows people living with HIV to enter the U.S. as visitors or immigrants.

Develop an incentive grant program through the CDC to encourage states to reverse laws that criminalize transmission of HIV disease. Incentive grants could include research grants that monitor changes in testing and risk behavior following repeal of HIV criminalization laws or prevention funding for correctional facilities that eliminate barriers to HIV testing, such as prosecution for criminal behaviors.